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Patient, Partner and Physician

PRINCIPAL INVESTIGATOR: Katrina Armstrong, M.D.

CONTRACTING ORGANIZATION: University of Pennsylvania
Philadelphia, Pennsylvania 19104-6205

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13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information) "Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. This project is using a cross-sectional survey to explore the role of the patient, partner and physician in treatment decisions and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. Many valuable steps have been taken in the first year of this grant, including the development of a pilot questionnaire, administration of the pilot questionnaire, development of the protocol for the study and development of patient, spouse and physician questionnaires. Enrollment for the study began in November, 2000.				
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Introduction

“Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician,” is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. We use a cross-sectional survey of patients, their spouses and their physicians to explore the role of the patient, partner and physician in treatment decisions, and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. By characterizing the role of the partner and the presence of significant misperceptions in the triad, and explicating the process of decision making under conditions of routine care, results of this project will serve as a basis for launching a research program in prostate cancer decision making. The guiding assumption of this work is that facilitation of communication and identification and resolution of misperceptions in the patient-partner-physician triad will improve patient satisfaction in decision making concerning localized prostate cancer.

Body

Task 1: Focus group discussions

Task 1 has been completed, as reported in our 2001 Annual Report

Task 2: Development of Survey Instruments

Task 2 has been completed, as we reported in our 2001 Annual Report. A final patient survey, partner survey, and doctor survey are included in this report (Appendix A, B and C).

Task 3: Preparation of Interim Reports and Manuscripts

The annual report is provided here. We are preparing manuscripts and have presented data from the study at the annual meeting of the Society for Medical Decision Making and the University of Pennsylvania Cancer Center Annual Scientific Symposium and Retreat. The abstract is included below.

Task 4: Cross-sectional survey

Development of data management system

After obtaining training in the use of Microsoft Access, a database was developed for the project. One database organizes eligible subjects' contact information and includes each subjects study ID number. A second database uses the study ID number to organize subject data without other identifiers. A system was developed for recording and checking subject eligibility and participation status and for entering all data.

Identification and recruitment of subjects

This task is complete, as we reported in our 2001 Annual Report. The process for identifying and recruiting potential subjects is completed and we are continuing to recruit subjects.

Enrolling subjects and telephone interviews

In November 2000, we began identifying consecutive patients and enrolling them in our study. To date, we have identified 159 patients from the Hospital of the University

of Pennsylvania (HUP) and 221 patients from the Philadelphia Veterans' Affairs Medical Center (VA). Mailed surveys, rather than phone interviews are being used to collect data from patients and partners

At HUP, 43 patients have been excluded: 3 because of mental disorders, 33 have declined participation, and 7 could not be contacted by telephone. Of the 116 HUP patients from whom we obtained oral, witnessed consent to participation, 83 (71%) completed study questionnaires. Seventy-one of these 83 patients have spouses, and 65 (91%) of the spouses completed a spouse questionnaire.

At the VA, 80 patients have been excluded: 19 because of mental disorders, 30 have declined participation, and 31 could not be contacted by telephone. Of the 126 VA patients from whom we obtained oral, witnessed consent to participation, 79 (62%) completed study questionnaires. Thirty-four of these 79 patients have spouses, and 27 (79%) of the spouses completed a spouse questionnaire. The 8 physicians at the VA have completed questionnaires about 69 of their patients.

Physician completion of questionnaire

After several meetings with participating physicians, a system was developed to facilitate physician completion of the study questionnaire. After discussing the diagnosis and treatment options with each study patient, physicians complete a brief questionnaire about that patient.

Data entry and quality control measures

Data are entered into the two databases described above. All entered data is checked against hard copies of patient information and surveys. Any detected errors are corrected. Data are backed up on a zip disk weekly with a new file name. This way, should a database become corrupted, a recent file version is available and can be easily updated with the most recent information. The data are also kept on a password protected computer.

Task 5: Interim Data Quality Assessment (descriptive statistics)

Descriptive statistics are generalized on an ongoing basis as data collection continues to ensure data quality. Data quality is also checked when the data are analyzed for conference presentations. See abstracts below for results from these analyses.

Key Research Accomplishments

- Continual accrual of newly diagnosed prostate cancer patients and data collection.
- Preliminary research findings
- Presentation of results at professional meetings
- Submission of manuscript on racial disparities in prostate cancer treatment outcomes (Appendix D)

Reportable Outcomes

- Three abstracts which were presented at the University of Pennsylvania Cancer Center Annual Scientific Symposium and Retreat, March 2002 (Abstracts below) which have been updated with the most recent data analyses
- Talk given at Society for Medical Decision Making, Baltimore MD, October 2002 (abstract below)
- Manuscript submitted (Appendix D)

ABSTRACT I:

TREATMENT DECISION FACTORS IN MEN WITH NEWLY DIAGNOSED PROSTATE CANCER

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and high-stakes, value-laden trade offs between higher survival rates and treatment side effects. How do patients weigh the many factors involved in prostate cancer treatment decisions and are these factors weighed differentially in those who choose surgery versus a nonsurgical treatment option? We investigated the importance of a series of decision factors in patients with newly diagnosed prostate cancer just after they had made their treatment decision. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (n=162). Table 1 shows the importance of each decision factor to all subjects, and a comparison of the importance of each decision factor to those who chose surgery versus those who chose a nonsurgical treatment. More than 85% of subjects reported that longevity, feeling certain that the cancer is completely gone, the "track record" of the treatment and their spouse's and urologist's opinion were very or extremely important in their decision. Chi Square tests comparing the importance of decision factors in those who chose surgery versus those who chose nonsurgical treatments revealed that the treatment's "track record" and impotence were rated as very or extremely important significantly more often in men choosing surgery ($p < .03$ for both comparisons). Keeping one's body intact and the cost of treatment were rated as very or extremely important significantly more often in men choosing a nonsurgical treatment ($p < .02$ for both comparisons). This study highlights several factors that influence decisions about treatment for localized prostate cancer. In the next year, we will continue to accrue patients and assess the relationship between these factors, treatment decisions, and long-term outcomes, such as decision satisfaction, satisfaction with treatment outcome, and quality of life.

Table 1. Importance of decision factors in all patients, and in patients choosing surgery versus a nonsurgical treatment

Decision Factor	% RESPONDING "VERY OR EXTREMELY IMPORTANT"			
	All patients (n=162)	Chose surgery (n=73)	Chose nonsurgical treatment (n=87)	χ^2 test (p value)
Longevity	91	93	89	>.05
Feeling certain that cancer is completely gone	92	99	86	.004
"Track record" of treatment	89	93	85	.005
Spouse's opinion	85	90	79	>.05
Urologist's opinion	86	88	84	>.05
Incontinence	83	85	81	>.05
How quickly the treatment works	66	68	64	>.05
Impotence	62	72	53	.013
Primary care doctor's opinion	65	60	69	>.05
Keeping my body intact	64	53	74	.007
Recovery time from treatment	56	51	59	>.05
Avoiding losing identity as a man	58	51	65	>.05
Discomfort of the treatment	41	35	45	>.05
Time it takes to get treatment	45	48	43	>.05
Family member's opinion	43	33	52	.038
Opinion of friend who has or had prostate cancer	40	31	49	.031
Risks of anesthesia	33	29	36	>.05
Cost of treatment	19	8	28	.003

ABSTRACT II:

INFORMATION-GATHERING PROCESS AND KNOWLEDGE OF TREATMENT OPTIONS IN MEN MAKING PROSTATE CANCER TREATMENT DECISIONS

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and the high-stakes, value-laden trade offs between higher survival rates and treatment side effects. What is the process that patients go through to gather information about their treatment options in order to make this difficult decision and how well informed are patients at the end of this process? We investigated the information-gathering process and resulting knowledge of treatment options in patients with newly diagnosed prostate cancer. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (n=162) after a treatment decision had been made. Nearly all patients report getting information about treatment options from their urologist (93%), although 36% report wishing they had received more information from the urologist. The timing of this discussion varied, occurring before biopsy results were available for 31%, during the same conversation when biopsy results were told for 22% and in a conversation after biopsy results were told for 47%. Twenty-one percent of patients reported getting a second opinion from another urologist and 72% report consulting with a radiation oncologist. Many patients also report getting information from their primary care doctor (52%), a friend/acquaintance who is a doctor (19%), prostate cancer survivors (52%), the internet (34%) and books/medical journals (58%). However, as shown in Figure 1, at the end of this information-gathering process, after patients had made their treatment decision, some patients report not having heard of some of the common treatment options. Over the next year, we will continue to accrue patients and explore potential causes of knowledge gaps, including patient ineligibility for a given treatment, patient sociodemographic characteristics, and provider characteristics.

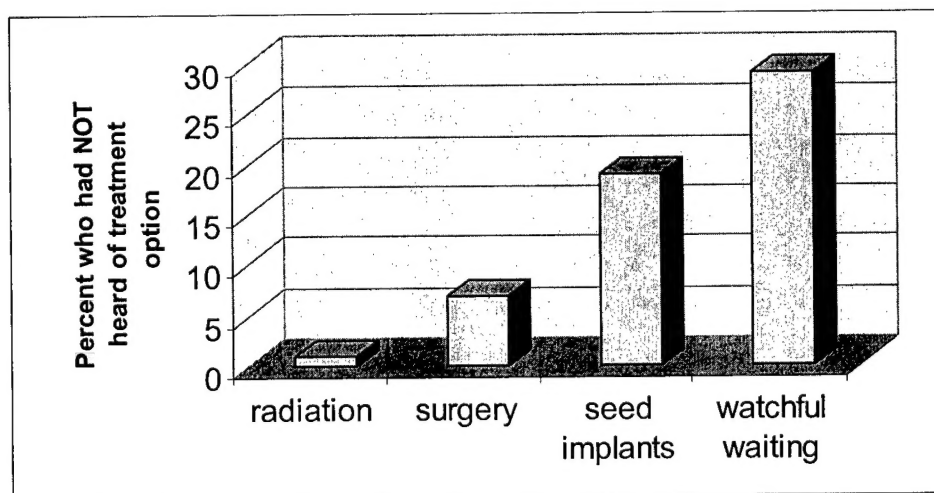


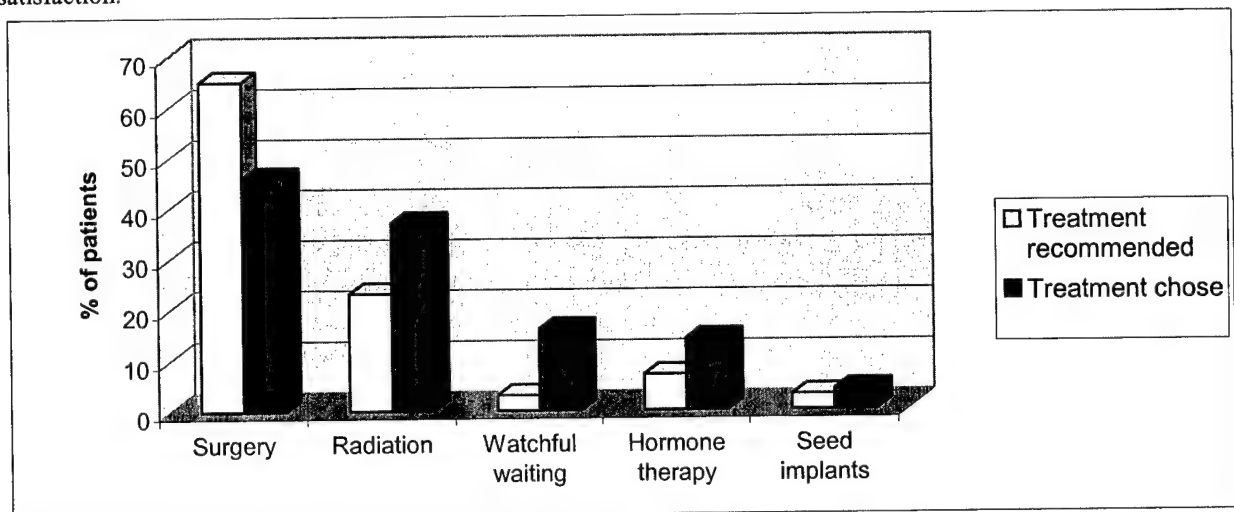
Figure 1. Patient knowledge of treatment options

ABSTRACT III:

THE ROLE OF UROLOGISTS' RECOMMENDATIONS IN TREATMENT DECISIONS OF MEN WITH NEWLY DIAGNOSED PROSTATE CANCER

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and high-stakes, value-laden trade offs between higher survival rates and treatment side effects. Physician recommendations can have a complex role in these medical decisions. On one hand, the difficulty of the decision may make patients more reliant on their physician's recommendation. On the other hand, the value-laden nature of the decision may lead patients to disregard the recommendation and to make their own treatment decision. In this study, we explored the role of the urologist's recommendation in the treatment decisions of men with newly diagnosed prostate cancer. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (VA) (n=162) after a treatment decision had been made. The 8 urologists of the VA patients also completed a survey about each of their newly diagnosed prostate cancer patients (n=8, who completed surveys for 113 patients). Eighty-five percent of patients report wanting to hear their urologist's recommendation, and 73% report receiving a recommendation, 52% of which were perceived to be very or extremely strong. The figure shows the percent of patients who report receiving a recommendation for each treatment option and the percent who chose each treatment option. Sixty-five percent of patients received a recommendation for surgery, 23% for radiation, 3% for watchful waiting, 7% for hormone therapy and 3% for seed implants. More patients than physicians believed that the patient had made the final treatment decision (72% versus 41% respectively). Although most patients report having made the final treatment decision, our data suggest that the physicians' recommendations nevertheless played a significant role in patients' treatment decisions. Over the next year, we will continue accruing patients (and at the VA, their respective physicians) and exploring the relationships between the role of the physician recommendation and patient characteristics and outcomes, such as decision satisfaction.



Abstract for talk at Society for Medical Decision Making (October, 2002):

The clinical reality of prostate cancer treatment decisions: is shared decision making really necessary?

Purpose: To examine urologists' role in prostate cancer patients' treatment decisions and urologists' accuracy at judging their patients' preferences and concerns. **Methods:** Surveys were completed by consecutive newly diagnosed prostate cancer patients (n=162) at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (VA) after a treatment decision had been made (55 days after diagnosis, on average). VA urologists (n=8) completed a survey for each of their newly diagnosed prostate cancer patients (n=74) immediately following their appointment.

Patients who report that they...	Surgery	XRT	Watchful Waiting	Seed implants	Hormone Tx
had not heard of tx option	8%	1%	28%	30%	23%
were recommended the tx option	64%	29%	3%	2%	3%
chose the tx option	46%	39%	12%	11%	7%

Results: The table above reports treatment awareness, recommendation and choice. 44% of patients wanted more information than they received and 75% wanted their urologist's recommendation. Patients who were recommended either surgery or XRT were more likely to choose that treatment than those who did not receive that recommendation (85% vs 9%, $p<.001$ surgery; 96% vs 20%, $p<.001$ XRT). Urologists underestimated their patients' desire for medical information ($p=.001$) and concern about impotence ($p=.03$), incontinence ($p=.002$) and getting the best chance of cure ($p=.002$). Although urologists rated their role in the decision as greater than patients rated their urologist on this variable, this difference did not reach statistical significance ($p=.069$). Urologists and patients did not differ in their rating of the patients' role preference in their decision or the strength of the urologist's recommendation ($p=.81$ and $p=.53$ respectively).

Conclusion: Although urologists' recommendations appear to strongly affect treatment choice, many urologists inaccurately estimate their patients' preferences and concerns. Many patients want more information than they receive and most want their urologist's recommendation. These limitations of current clinical practice emphasize the importance of shared decision making in prostate cancer treatment

Conclusions

The past year has been productive and informative for this study. We have continued to enroll subjects into our study and have achieved an overall response rate of 64% across both hospitals. We have continued to conduct preliminary analyses of the data and have presented the data at relevant conferences, as described above.

Appendix A: Patient survey

**MEN'S HEALTH CARE
DECISION MAKING
STUDY**

**FOR YOU
TO COMPLETE**

Thank you very much for your help.

Please return in the enclosed envelope.

Instructions

This questionnaire asks about your experiences with the diagnosis of prostate cancer and deciding on a treatment. Your answers will be kept strictly confidential.

Please fill out this questionnaire without talking to your partner. We are interested in YOUR thoughts, even on the questions that ask about your partner.

If you have any questions, please feel free to contact Andrea Gurmankin at 215 573-9722. Thank you in advance for your participation.

Date you are filling out this questionnaire: ____/____/____

Who is your urologist? _____ (Your doctor will never see your responses)

Part A. The first set of questions asks about your treatment decision.

- 1) Which of the following possible treatments for prostate cancer have you **heard** of?
(check **all** that you have heard of)
 - ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
 - ☐ Radiation therapy
 - ☐ Seed implants (Brachytherapy)
 - ☐ Hormone therapy
 - ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)
- 2) Which treatment have you chosen? (check **all** that apply)
 - ☐ Surgery
 - ☐ Radiation therapy
 - ☐ Watchful waiting
 - ☐ Seed implants
 - ☐ Hormone therapy
 - ☐ Other (Please explain):
- 3) Approximately when did you make your final decision about which treatment you would get for your prostate cancer? This includes deciding on watchful waiting. (Please just give your best estimate).
____/____/____ ☐ I have not decided which treatment I will get
- 4) Approximately when did you begin treatment or when do you expect to begin treatment for prostate cancer?
____/____/____

Please continue to the next page →

5) Please tell us how important each of the following factors were in your prostate cancer treatment decision, and then circle the one that was the most important factor in your decision.					
	Extremely important	Very important	Somewhat important	Slightly important	Not at all important
a) possibility of impotence (inability to get or maintain an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) possibility of incontinence (trouble controlling your urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) feeling certain that the cancer is completely gone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) keeping my body intact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) avoiding losing my identity as a man	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) desire to live as long as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) cost of the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) discomfort of the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) time it takes to get the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) how long it takes to recover from the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) "track record" of the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) how quickly the treatment works	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) my urologist's opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) my primary care doctor's opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) my partner's opinion (<i>leave blank if you don't have a partner</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) another family member's opinion (how are you related to this person?): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) opinion of a friend or acquaintance who has or has had prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) information from other sources (what sources?):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) other (please explain):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6) Now please circle the letter beside the one factor listed **above in question 5** that was the **most important factor** in your treatment decision.

- 7) What have you done to get information about your treatment options? (*check all that apply*)
- ☐ Speak to my doctor
 - Which doctor(s)? ☐ Urologist ☐ Primary care doctor ☐ Other
 - ☐ Speak to friend/acquaintance who is a doctor
 - ☐ Speak to prostate cancer survivors
 - ☐ Get information on the internet
 - ☐ Get information in books/medical journals
 - ☐ Other (Please explain below where else you got information):
- 8) Which statement best describes how much medical information you want?
- ☐ I want *only* the information needed to care for myself properly
 - ☐ I want additional information only if it is *good* news
 - ☐ I want as *much* information as possible, good and bad
- 9) Which statement best describes the role you want to play in your medical decisions?
- ☐ I prefer to leave the decision to my doctor
 - ☐ I prefer that my doctor make the final decision after seriously considering my opinion
 - ☐ I prefer that my doctor and I share responsibility for making the decision
 - ☐ I prefer to make the final decision after seriously considering my doctor's opinion
 - ☐ I prefer to make the final decision on the basis of the facts I learn from my doctor and elsewhere, without considering my doctor's opinion

Part B. The next questions ask about when you were first diagnosed with prostate cancer.

- 1) Which doctor did you **first** speak to about whether you should get a biopsy to look for prostate cancer?
- ☐ My primary care doctor ☐ A friend/acquaintance who is a doctor
 - ☐ A urologist ☐ Other (Please explain):
- 2) When your doctor mentioned getting a prostate biopsy, did he/she **ask your opinion** about the idea?
- ☐ Yes ☐ No
- 3) Which doctor did you **first** speak to about your treatment options for prostate cancer?
- ☐ My primary care doctor ☐ A friend/acquaintance who is a doctor
 - ☐ A urologist ☐ Other (please explain):
- 4) When did this conversation occur?
- ☐ during an appointment or conversation **before I got my biopsy results**
 - ☐ **during** the same appointment or conversation in which I **got my biopsy results**
 - ☐ during an appointment or conversation at some point **after I got my biopsy results**
 - ☐ Other (please explain):
- 5) Was your partner present during this conversation?
- ☐ Yes ☐ No ☐ I have no partner

If the first time you talked to a doctor about treatment options was NOT with a urologist:

- 6) a) When was the main conversation you had with a urologist about your treatment options?
- ☐ during an appointment or conversation **before I got my biopsy results**
 - ☐ **during** the same appointment or conversation in which I got my biopsy results
 - ☐ during an appointment or conversation at some point **after I got my biopsy results**
 - ☐ Not applicable
 - ☐ Other (please explain):
- b) Was your partner present during this conversation about treatment options with the urologist?
- ☐ Yes ☐ No ☐ I have no partner

Part C. The next set of questions asks more about your conversation with your urologist about treatment options. If you have not yet spoken to your urologist about treatment options, please skip to Part D.

- 1) Approximately what was the date of your conversation with your urologist about your treatment options? (please give your best estimate) ____/____/____
- 2) About how much time did you spend talking with the urologist about your treatment options? (please give your best estimate) ____ minutes
- 3) Would you have preferred to spend more or less time talking with the urologist? (Please circle a number below)
- | | | | | |
|-----------|---------------|-----------------------|---------------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | A little less | Neither more nor less | A little more | Much more |
- 4) Did the urologist mention the option of →
- | | | |
|-------------------------------|------------------------------|-----------------------------|
| a) getting surgery? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| b) getting radiation therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| c) getting seed implants? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| d) getting hormone therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| e) watchful waiting? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
- 5) Would you have preferred more or less information from the urologist? (Please circle a number below)
- | | | | | |
|-----------|---------------|-----------------------|---------------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | A little less | Neither more nor less | A little more | Much more |
- 6) If you had any questions for the urologist, did you feel free to ask your questions?
- ☐ I did not have any questions ☐ Yes ☐ No → Why not?:

- 7) Did your urologist give you **information about your chance of cure** using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?
☐ No numbers/only words ☐ Some numbers/some words
☐ Only numbers/no words ☐ No information given about chance of cure
- 8) Would you have preferred that your doctor use words, numbers or both to explain your chance of cure?
☐ Words ☐ Numbers ☐ Both ☐ No preference
- 9) Did the urologist recommend a particular treatment to you? ☐ Yes ☐ No

If yes →

a) What was the urologist's primary treatment recommendation?

- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (Please explain):

b) How strong was the urologist's recommendation? (*circle one number*)

- | | | | | |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all
strong | Slightly
strong | Somewhat
strong | Very
strong | Extremely
strong |

- 10) Did you want the urologist to provide a recommendation? ☐ Yes ☐ No
- 11) Which treatment option did you favor BEFORE hearing the urologist's recommendation?
☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (Please explain):
- 12) Did the urologist suggest that you speak to a radiation oncologist? ☐ Yes ☐ No
- 13) Did you speak with a radiation oncologist? ☐ Yes ☐ No
- 14) Did you get a second opinion from another urologist? ☐ Yes ☐ No
- 15) Which of the following best describes how the decision about your prostate cancer treatment was made?
☐ My urologist made the final decision
☐ My urologist made the final decision after seriously considering my opinion
☐ My urologist and I shared responsibility for the final decision
☐ I made the final decision after seriously considering my urologist's opinion
☐ I made the final decision on the basis of the facts I learned from my urologist and elsewhere, without considering my urologist's opinion

Part D. The next questions ask your thoughts about different treatments and side effects.

1) How concerned are <u>you</u> about:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
a) experiencing impotence (trouble getting or maintaining an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) experiencing incontinence (trouble controlling your urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) experiencing risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) getting the best chance of cure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2) Please rate what you think your chance of **impotence** would be if you were to get **each** of the following treatments. For each one, assume you are **ONLY** getting that one treatment.

	Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely
a) Radical prostatectomy (surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hormone therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Seed implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Watchful waiting (no treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3) Please rate what you think your chance of **incontinence** would be if you were to get **each** of the following treatments. For each one, assume you are **ONLY** getting that one treatment.

	Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely
a) Radical prostatectomy (surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hormone therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Seed implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Watchful waiting (no treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4) Please rate what you think your chance of **cure** would be if you were to get **each** of the following treatments. For each one, assume you are **ONLY** getting that one treatment.

	Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely
a) Radical prostatectomy (surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hormone therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Seed implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Watchful waiting (no treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part E. Next we ask about what you think YOUR PARTNER thinks about different treatment options. We also ask about the discussions you two had about your options. *If you do not have a partner, skip to Part F. Please remember to respond without input from your partner.*

1) How concerned <u>do you think your partner</u> is about you:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
a) experiencing incontinence (trouble controlling your urine)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) experiencing impotence (trouble getting or maintaining an erection)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) getting the best chance of cure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2) Which treatment do **you think your partner** thinks has the best chance of cure for you?

- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner thinks
☐ They all have the same chance of cure

3) If it had been up to **your partner**, which treatment do you think she would have chosen for you?

- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner would have chosen
☐ Other (please explain):

4) How does **your partner** feel about the treatment that was chosen?

- ☐ Insisted that I get it ☐ Opposed the decision
☐ Supported the decision ☐ Insisted that I not get it
☐ I don't know how my partner feels
☐ Other (please explain):

Please continue to the next page →

- 5) How often did you and your partner discuss your treatment options? *(please circle a number below)*
- | | | | | |
|-------|--------|--------------|-------------|------------|
| 1 | 2 | 3 | 4 | 5 |
| Never | Seldom | Now and then | Quite often | Very often |

- 6) Would you have preferred to discuss your treatment options with your partner more or less? *(please circle a number below)*
- | | | | | |
|-----------|---------------|-----------------------|---------------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | A little less | Neither more nor less | A little more | Much more |

If you responded "never" to question 5, skip to question 10. Otherwise, continue to question 7.

- 7) When you had these discussions about treatment options, who initiated them?
- ☐ Me ☐ My partner ☐ We both initiated some of the discussions.

- 8) How satisfied were you with those discussions? *(please circle a number below)*
- | | | | | |
|-------------------|-----------------------|------------------------------------|--------------------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Very dissatisfied | Somewhat dissatisfied | Neither satisfied nor dissatisfied | Somewhat satisfied | Very satisfied |

- 9) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? *(please circle a number below)*
- | | | | | |
|-------|--------|--------------|-------------|------------|
| 1 | 2 | 3 | 4 | 5 |
| Never | Seldom | Now and then | Quite often | Very often |

- 10) How strongly did you want your partner's opinion to be factored into your treatment decision? *(please circle a number below)*
- | | | | | |
|------------|----------|----------|------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | A little | Somewhat | Very | Extremely |

Please continue to the next page →

11) The following statements focus on the way your partner deals with the fact that you have prostate cancer. Please indicate to what extent your partner does or does not act in the ways described.					
	Never	Seldom	Now and then	Quite often	Very often
a) My partner tries to discuss it with me openly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) My partner asks me how I feel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) When something bothers me, my partner tries to discuss the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) My partner is full of understanding towards me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) My partner makes me feel that I'm not alone in this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) My partner tries to persuade me to follow the doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) My partner tries to hide his or her worries about me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) My partner tries to act as if nothing is the matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) My partner gives in when I make an issue of something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) My partner just waves my worries aside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) My partner does everything to prevent me from thinking about my disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) My partner can't endure me being concerned and acts as if she doesn't notice my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) My partner takes over as much of my work as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue to the next page →

Part F. This set of questions asks about your feelings of conflict over your prostate cancer treatment decision. The statements below are things that some people say when they have just made a difficult decision. Thinking about decision, please check the box that best matches how much you agree with each statement.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1) I feel I have made an informed choice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) My decision shows what is most important for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) I expect to stick to my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) I am satisfied with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) This decision was hard for me to make	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) I was unsure what to do in this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) It was clear what choice was best for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) I am aware of the choices I have to manage my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) I feel I know the benefits of the treatments for prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) I feel I know the risks and side effects of treatment for prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I need more advice and information about the choices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) I know how important the benefits of the treatment for prostate cancer are to me in this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) I felt pressure from others in making this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) I had the right amount of support from others in making this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part G. The next questions ask about your background.

- 1) What is your age? _____ years
 - 2) What is your race?
☐ African-American ☐ Caucasian ☐ Hispanic
☐ Asian-American ☐ Other (please specify) _____
 - 3) What level of education have you completed? (*Circle one number*)
9 10 11 12 13 14 15 16 17 18 19 20 21+
high school college graduate school
 - 4) Which of the following conditions have you had in the past 12 months?
(*check all that apply*)

<input type="checkbox"/> high blood pressure	<input type="checkbox"/> heart trouble
<input type="checkbox"/> diabetes	<input type="checkbox"/> emotional or mental illness
<input type="checkbox"/> stroke	<input type="checkbox"/> chronic bronchitis
<input type="checkbox"/> asthma	<input type="checkbox"/> arthritis or rheumatism
<input type="checkbox"/> cancer (other than prostate)	<input type="checkbox"/> epilepsy
<input type="checkbox"/> chronic nervous trouble	<input type="checkbox"/> tuberculosis
<input type="checkbox"/> hernia or rupture	<input type="checkbox"/> chronic liver problem
<input type="checkbox"/> drinking problems or alcoholism	<input type="checkbox"/> chronic gallbladder trouble
<input type="checkbox"/> stomach ulcer or duodenal ulcer	
 - 5) Are you currently experiencing impotence? ☐ Yes ☐ No
 - 6) Are you currently experiencing incontinence? ☐ Yes ☐ No
 - 7) Do you currently have health insurance? ☐ Yes ☐ No ☐ Not sure
- 7a) *If yes* ➤ please check the type of plan that best describes your current health insurance:
- ☐ Fee-for-service plan where you can go to any doctor or hospital
 - ☐ HMO where your primary care doctor refers you to specialists
 - ☐ PPO where you can go to any doctor or hospital on a list without getting a referral
 - ☐ I don't know which type of plan I have

Part H. This section asks about your relationship with your partner. If you do not have a partner, skip to Part I.

1) Most people have some disagreements in their relationships. Below is a series of issues. We'd like you to tell us of any disagreement experienced between you and your partner over each of these issues in a typical month (this past month may not have been typical for you, since you were just diagnosed with prostate cancer). So for each issue, please tell us in a typical month, how much you have agreed or disagreed about....

In a typical month, my partner and I have	Always agreed	Almost always agreed	Occasionally agreed	Frequently disagreed	Almost always disagreed	Always disagreed
a) religious matters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) demonstration of affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) sex relations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) conventionality (correct or proper behavior)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) making major decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) career decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2) How often do you and your partner do the following things:	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
a) discuss or consider divorce, separation, or terminating your relationship?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) regret that you married?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) quarrel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) "get on each other's nerves?"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Every day	Almost every day	Occasionally	Rarely	Never
3) How often do you and your partner engage in outside interests together?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Below are some things that you and your partner might do. Please tell us how often you think they occur between you and your partner.

	More than once a day	Once a day	Once or twice a week	Once or twice a month	Less than once a month	Never
4) Have a stimulating exchange of ideas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Calmly discuss something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Work together on a project	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) How often does your partner go with you to your doctors' appointments?

1 2 3 4 5
 Never Once in a while Sometimes Frequently Always

8) How long have you and your partner been together? _____ years

Part I. This last section asks about your quality of life.

1) During the past four weeks how much of the time ...	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) have you been concerned or worried about loss of muscle tone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) did you have negative feelings about the way your body looks?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) did you avoid being seen without a shirt on?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) did you feel that your body was getting soft and flabby?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) were you concerned or worried about difficulty getting or keeping an erection?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) did you wish you could regain your sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) did you feel frustrated about your sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) did you feel despair over the loss of sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Skip to question 3 if you do not have a partner

2) How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true no false	Mostly false	Definitely false
a) I felt uncomfortable when my partner wanted to hug or kiss me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I felt affectionate about my partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I felt that my partner was not satisfied with our sex life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I felt that my partner may want to turn to others for affection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) My partner was worried about my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I worked hard to keep my partner from worrying about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3) How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true no false	Mostly false	Definitely false
a) Since I've had cancer I feel that I have lost my ability to be aggressive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I feel that I've lost part of my manhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I feel as if I'm going through a "change of life" like women do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I feel that what I say is not taken very seriously by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4) During the past four weeks how much of the time ...	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) did you feel that your cancer kept you from being the friend you wanted to be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) did you feel that other people don't really understand what it's like to have prostate cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) did you feel that you were a bother to other people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) did you worry about eventually becoming unable to take care of yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) did you worry about your cancer, but keep it to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
f) did you feel that others who are close to you try to hide their true feelings about your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) did you feel that others think less of you because of your health problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) have you felt weak and small?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) have you worried about the cancer spreading?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) have you thought about your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) have you worried about dying soon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) have you been concerned about side-effects of your cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) have you felt that your cancer has given you a better outlook on your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) have you felt that coping with your cancer has made you a stronger person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) have you wished that you could change your mind about the kind of treatment you chose for your prostate cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5) How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true nor false	Mostly false	Definitely false
a) I feel that I would be better off if I had chosen another treatment for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) It bothers me that other men with prostate cancer get treatment that is very different from what I will receive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your participation. Please mail the completed survey in the enclosed, stamped, addressed envelope.

Appendix B: Partner survey

**MEN'S HEALTH CARE
DECISION MAKING
STUDY**

**FOR YOUR
PARTNER
TO COMPLETE**

Thank you very much for your help.

Please return in the enclosed envelope.

Instructions:

This questionnaire asks about your experiences with your spouse or partner's diagnosis of prostate cancer and deciding on a treatment. Your answers will be kept strictly confidential.

Please fill out this questionnaire without any communication between you and your partner. We are interested in YOUR thoughts, even on the questions that ask about your partner.

If you have any questions, please feel free to contact Andrea Gurmankin at 215 573 9722. Thank you in advance for your participation.

Date you are filling out this questionnaire: ____/____/____

- 1) Which of the following possible treatments for prostate cancer have you **heard** of?

(check **all** that you have heard of)

- ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
- ☐ Radiation therapy
- ☐ Seed implants (Brachytherapy)
- ☐ Hormone therapy
- ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)

- 2) Please rate what you think your partner's chance of **impotence** would be if he were to get **each** of the following treatments. For each one, assume he is **ONLY** getting that one treatment.

	Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely
a) Radical prostatectomy (surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hormone therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Seed implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Watchful waiting (no treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue to the next page →

- 3) Please rate what you think your partner's chance of **incontinence** would be if he were to get **each** of the following treatments. For each one, assume he is **ONLY** getting that one treatment.

	Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely
a) Radical prostatectomy (surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hormone therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Seed implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Watchful waiting (no treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 4) Please rate what you think your partner's chance of **cure** would be if he were to get **each** of the following treatments. For each one, assume he is **ONLY** getting that one treatment.

	Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely
a) Radical prostatectomy (surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Hormone therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Seed implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Watchful waiting (no treatment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Questions 5-8 ask about YOUR thoughts about different prostate cancer treatments and their possible side effects

How concerned are <u>you</u> about your partner:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
5) experiencing impotence (trouble getting or maintaining an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) experiencing incontinence (trouble controlling his urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) experiencing risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) getting the best chance of cure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 9) If it had been up to you, which treatment would you have chosen for your partner?
- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (please explain):

Questions 10-13 ask about YOUR thoughts about what your PARTNER thinks about different treatments and possible side effects.

How concerned <u>do you think your partner</u> is about:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
10) experiencing incontinence (trouble controlling his urine)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) experiencing impotence (trouble getting or maintaining an erection)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) getting the best chance of cure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14) Which treatment do you think your partner thinks has the best chance of cure for him?

- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (please explain):

The next section asks about the discussions that you and your partner had about treatment options.

15) How often did you and your partner discuss his treatment options? (*please circle a number below*)

- 1 2 3 4 5
 Never Seldom Now and then Quite often Very often

16) Would you have preferred to discuss his treatment options more or less? (*please circle a number below*)

- 1 2 3 4 5
 Much less A little less Neither more nor less A little more Much more

If you responded "never" to question 15, skip to question 19. Otherwise, continue to # 17.

17) When you had these discussions about treatment options, who initiated them?

- ☐ Me ☐ My partner ☐ We both initiated some of the discussions.

18) How satisfied were you with those discussions? (*please circle a number below*)

- 1 2 3 4 5
 Very dissatisfied Somewhat dissatisfied Neither satisfied nor dissatisfied Somewhat satisfied Very satisfied

19) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? (*please circle a number below*)

- 1 2 3 4 5
 Never Seldom Now and then Quite often Very often

The following statements focus on the way you deal with the fact that your partner has prostate cancer. Please indicate to what extent you do or do not act in the ways described.					
	Never	Seldom	Now and then	Quite often	Very often
20) I try to discuss it with my partner openly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) I ask my partner how he feels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) When something bothers my partner, I try to discuss the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) I am full of understanding towards my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24) I make my partner feel that he is not alone in this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25) I try to persuade my partner to follow the doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26) I try to hide my worries about my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27) I try to act as if nothing is the matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28) I give in when my partner makes an issue of something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29) I just wave my partner's worries aside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30) I do everything to prevent my partner from thinking about his disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31) I can't endure my partner being concerned and act as if I do not notice my partner's worries.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32) I take over as much of my partner's work as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 33) How strongly did you want your opinion to be factored into your partner's treatment decision? *(Circle a number below)*
- | | | | | |
|------------|----------|----------|------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | A little | Somewhat | Very | Extremely |
- 34) How satisfied are you with the information you have about your partner's prostate cancer diagnosis and treatment options? *(Circle a number below)*
- | | | | | |
|-------------------|-----------------------|------------------------------------|--------------------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Very dissatisfied | Somewhat dissatisfied | Neither satisfied nor dissatisfied | Somewhat satisfied | Very satisfied |

This last section asks a few questions about you.

35) What is your age? _____ years

36) What is your race?

☐ African-American

☐ Caucasian

☐ Hispanic

☐ Asian-American

☐ Other (please specify) _____

37) What level of education have you completed? (*Circle a number below*)

9 10 11 12

13 14 15 16

17 18 19 20 21+

high school

college

graduate school

**Thank you for your participation. Please mail the completed survey
in the enclosed, stamped, addressed envelope.**

Appendix C: Physicians Survey

Date ____/____/____

Patient name _____

Please fill out after telling patient of his positive prostate biopsy and his treatment options.

1) Which of the following treatment options did you mention to the patient?

getting surgery	<input type="checkbox"/> Yes	<input type="checkbox"/> No	getting hormone therapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No
getting radiation therapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No	watchful waiting	<input type="checkbox"/> Yes	<input type="checkbox"/> No
getting seed implants	<input type="checkbox"/> Yes	<input type="checkbox"/> No			

2) Did you recommend a particular treatment to the patient? ☐ Yes ☐ No (*If no, skip to #5*)

3) What was your **primary** recommendation (*check one*)?

<input type="checkbox"/> Radical prostatectomy	<input type="checkbox"/> Radiation therapy	<input type="checkbox"/> Hormone therapy
<input type="checkbox"/> Brachytherapy	<input type="checkbox"/> Watchful waiting	<input type="checkbox"/> Other (Please explain):

4) How strong was your recommendation for this treatment option? (*check one option*)

<input type="checkbox"/> Not at all strong	<input type="checkbox"/> Slightly strong	<input type="checkbox"/> Somewhat strong	<input type="checkbox"/> Very strong	<input type="checkbox"/> Extremely strong
---	---	---	---	--

5) Do you think the patient would have preferred more or less information from you? (*choose one*)

1 Much less	2 A little less	3 Neither more nor less	4 A little more	5 Much more
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6) Do you think the patient asked all of the questions that he had? ☐ Yes ☐ No

7) Which statement best describes how much medical information this patient wants?

☐ He wants *only* the information needed to care for himself properly.
☐ He wants additional information only if it is *good* news.
☐ He wants as *much* information as possible, good and bad.

8) Which statement best describes the role this patient wants to play in his medical decisions?

☐ He prefers to leave the decision to his doctor
☐ He prefers that the doctor make the final decision after seriously considering his opinion
☐ He prefers that he and the doctor share responsibility for making the decision
☐ He prefers to make the final decision after seriously considering the doctor's opinion.
☐ He prefers to make the final decision on the basis of the facts he learns from the doctor and elsewhere, without considering the doctor's opinion.

9) Did you suggest that the patient speak to a radiation oncologist? ☐ Yes ☐ No

continue to next page →

WIN A DINNER AT LE BEC FIN

Every time you fill out a questionnaire, we will enter you in a raffle to win a \$150 gift certificate to Le Bec Fin. Write your name below, and we will enter this slip into the drawing. The next drawing will be in June, and we will contact the winner by email.

Name: _____ email (only necessary to give us once): _____

10) Compared to other newly diagnosed prostate cancer patients, how much did this patient ask questions or elicit information about his diagnosis, treatment options and/or prognosis?

1 2 3 4 5
 Much less A little less Neither more A little more Much more
 than others than others nor less than others than others

11) How concerned do you think this patient is about:	Extremely	Very	Somewhat	Slightly	Not at all	I don't know
a) experiencing impotence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) experiencing incontinence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) experiencing risks of anesthesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) getting the best chance of cure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12) Did you give the patient **information about his chance of cure** using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?

- ☐ No numbers/only words ☐ Some numbers/some words
☐ Only numbers/no words ☐ No information given about chance of cure

13) Using the response options below, please rate what you think this patient's chance of **cure** would be if he were to get **each** of the following treatments? For each treatment, assume he is **ONLY** getting that one treatment. (*Enter 1 for not at all likely, 2 for slightly likely, 3 for somewhat likely, 4 for very likely and 5 for extremely likely*).

_____ Radical prostatectomy _____ Radiation therapy _____ Hormone therapy
 _____ Brachytherapy _____ Watchful waiting

14) Which best describes how the patient's treatment decision was made?

- ☐ I made the final decision
☐ I made the final decision after seriously considering the patient's opinion
☐ The patient and I shared responsibility for the final decision.
☐ The patient made the final decision after seriously considering my opinion.
☐ The patient made the final decision on the basis of the facts he learned from me and elsewhere, without considering my opinion.
☐ I don't know (because the patient made the decision with another doctor)
☐ The decision has not been made yet

Thank you for completing our questionnaire.

Appendix D: Submitted Manuscript

Racial Differences in Prostate Cancer Treatment Outcomes: A Systematic Review

Race & Prostate Cancer Treatment Outcome

Nikki Peters, B.A., Katrina Armstrong, M.D., M.S.C.E.¹⁻⁵

- (1) Department of Medicine, University of Pennsylvania School of Medicine
- (2) Abramson Cancer Center, University of Pennsylvania School of Medicine
- (3) Center for Clinical Epidemiology and Biostatistics, University of Pennsylvania School of Medicine
- (4) Leonard Davis Institute of Health Economics, University of Pennsylvania
- (5) Center for Health Equity Research and Promotion, Philadelphia VA Medical Center

Direct correspondence to: Nikki Peters

1134 Blockley Hall, 423 Guardian Drive
Philadelphia, PA 19104-6021
tel: (215) 5783-7907
fax: (215) 573-8779
email: npeters@mail.med.upenn.edu

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Condensed Abstract. The majority of studies in this review found no difference in prostate cancer treatment outcome between races. This suggests that differences in outcomes after treatment do not play a substantial role in racial disparities in prostate cancer survival.

Abstract

Background. Prostate cancer mortality is twice as high in black men compared to white men. The existence of differences in cancer incidence and treatment between black and white men is widely accepted. However, the existence of racial differences in treatment outcomes remains controversial. We conducted a systematic review of racial disparities in prostate cancer treatment outcomes.

Methods. A literature search was conducted using the terms: “prostate cancer” (keyword) or “prostate neoplasm” (subject heading) + “blacks” (subject heading) or “blacks” (keyword).

Results. 258 eligible articles were identified; twenty-nine were selected. All but three studies were retrospective. Seven (24%) studies were conducted at Veteran Affairs medical centers. Treatment included: radical prostatectomy (12 studies), hormonal therapy (5 studies), radiotherapy (9 studies), and a combination of interventions (3 studies). The majority of studies (80%) observed no significant difference in treatment outcomes between races. The remainder found worse outcomes among black men, including worse five year survival (HR range 2.35-96.74) and higher rates of PSA failure (OR range 1.15-1.69).

Conclusions. The majority of studies investigating racial differences in prostate cancer treatment outcomes in the past ten years found no difference between races after controlling for tumor and patient characteristics. This suggests that differences in outcomes after treatment do not play a substantial role in racial disparities in prostate cancer survival. Efforts to narrow the gap between black and white prostate cancer mortality should focus on ensuring patients of all races receive optimal treatment and reducing incidence and extent of disease at presentation among black men.

Keywords: prostate neoplasm, treatment outcome, Blacks, review

Introduction

Prostate cancer is the most common non-dermatological cancer among men in the United States, and the second most common cause of cancer death. In 2002 189,000 men were diagnosed with prostate cancer and 30,200 died from the disease [1]. Black men are two and a half times more likely to die of prostate cancer than white men [2]. From 1995 to 1999, U.S. age-adjusted death rates for prostate cancer were 72.8 per 100,000 for black men and 31.2 per 100,000 for white men [3].

The causes of the increased prostate cancer mortality among black men are only partly understood. Prostate cancer incidence is higher in black men. Surveillance, epidemiology, and end results (SEER) 1995-1999 incidence rates were 266.8 for black men and 163.2 for white men, per 100,000 [3]. This difference in incidence has been attributed to factors such as diet, genetic variability and socioeconomic status [4-8]. Black men are more likely to be diagnosed with an advanced stage disease and with higher PSA levels than white men [9-13]. Among patients diagnosed with localized prostate cancer, black men have been consistently found to be less likely to undergo radical prostatectomy and more likely to be managed by watchful waiting [14, 15]. Although many experts believe this difference in treatment contributes to the difference in survival, this link remains controversial because of the lack of definitive data about the effect of radical prostatectomy on prostate cancer survival.

In addition to differences in incidence, extent of disease at presentation and type of treatment, racial differences in outcomes after treatment may contribute to differences in mortality. However, the existence of racial disparities in prostate cancer treatment outcomes remains controversial [15-17]. Thus, we conducted a review of

literature on racial disparities in prostate cancer treatment outcomes over the past ten years.

Methods

A systematic literature search was conducted on studies published in the past 10 years, 1992-2002, using Medline, CancerLit, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. The following search was conducted: “prostate cancer” (keyword) or “prostate neoplasm” (subject heading) + “blacks” (subject heading) or “blacks” (keyword). The search resulted in 258 articles. Relevant articles were selected by reviewing titles and/or abstracts. Reference sections were reviewed to identify additional relevant articles. Selection criteria included: 1) published between 1992 and 2002; 2) published in English; and 3) specifically addressed prostate cancer treatment outcome results between black and white men.

A total of 29 articles were selected. Data extraction was completed independently by two investigators. Disagreements were resolved through discussion. Data elements included: Year of publication, research design, sample size and time frame of collection, disease stage, treatment, study location, measured outcomes, and factors that were adjusted.

Results

A summary of the literature is presented in Table 1. All but three of the studies were retrospective. Twelve (41%) studies investigated radical prostatectomy alone outcomes, nine (31%) studies investigated radiotherapy alone, and five (17%) studies

investigated hormonal therapy alone. Three (10%) of the studies included multiple interventions. Six (21%) studies included metastatic prostate cancer patients in the sample population. Blacks made up at least 20% of the sample size in twenty (69%) of the studies. Seven (24%) of the studies were conducted at Veteran's Affairs medical centers. Thirteen studies (45%) measured PSA failure, five (17%) measured overall survival, three (10%) measured disease-free survival, and eight (28%) measured a combination of outcomes. Confounding factors that were controlled for differed among studies and many (48%) controlled for age of onset, stage and grade of the disease. Twenty-three (80%) of the studies reported numeric measures of the strength of association between race and outcome, while six studies reported only p-values.

Overall, 23 (80%) of the 29 studies reported no difference in treatment outcomes among white and blacks; six (20%) studies found that blacks had worse outcomes than whites. No study found that whites had worse outcomes than blacks. In studies that found worse outcomes among blacks, blacks had worse five-year survival with hazard ratios ranging from 2.35-96.74 and higher rates of PSA failure with odds ratios ranging from 1.15-1.69. Three additional studies identified racial differences in outcomes among subgroups. One study found a higher disease recurrence rate in younger black men (age 50-69), but no racial differences among men 70-79 years (Powell 1999). While another study reported worse outcomes, including higher recurrence rates, in black men with non-organ confined cancer, but not in black men with organ confined cancer [18]. A third study reported worse survival in black men with stage III prostate cancer, but not stages I or II [19].

Although the number of studies was too small to permit inferential statistics, studies that found a racial difference in treatment outcomes differed on several characteristics from the studies that did not find racial differences (Table 2). Thirty-three percent of the studies that found a racial difference (2/6) were published in 1996 or previously compared to 17% of studies that did not find a racial difference (4/23). Similarly, 33% of studies (2/6) finding a racial difference included patients with metastatic disease, whereas only 17% of studies (4/23) that did not find a racial difference included patients with metastatic disease. Only one study (17%) that found a racial difference in survival included patients who received primary radiation therapy compared to 11 studies (48%) that did not find a racial difference in outcome.

Discussion

Between 1995 and 1999 U.S. age-adjusted death rates for prostate cancer were 72.8 per 100,000 for black men and 31.2 per 100,000 for white men [3]. In terms of absolute and relative difference in mortality, prostate cancer presents the greatest disparity in mortality between blacks and whites of any cancer in the US. Understanding the causes of this disparity is an important next step in developing effective strategies to reduce prostate cancer mortality among black men. Although racial differences in the incidence of disease and treatment are widely recognized, the existence of racial differences in outcomes after treatment have been more controversial.

The results of this review suggest that racial disparities in prostate cancer mortality are not the result of treatment outcomes. Eighty percent of studies of the association between race and prostate cancer treatment outcomes published from 1992

to 2002 concluded that race is not an independent predictor of treatment outcome. This finding held for studies of overall survival, disease-specific survival and PSA relapse, as well as many different types of study sites, including Veterans Affairs Medical Centers. Only 20% of studies found an overall association between black race and worse treatment outcomes, although an additional 13% of studies found an association between race and outcome in subgroups of patients, including men with Stage III or locally advanced disease and younger men.

These findings have several implications for how best to reduce prostate cancer mortality among black men. We need a better understanding of the factors that drive the high incidence rates among black men. Ongoing research into genetic and lifestyle differences may elucidate part of this puzzle. Furthermore, it is not well understood why black men present with higher PSA levels, at a younger age, and more extensive disease than white men [10, 20, 21]. Although genetic and lifestyle variation may also contribute to these differences, the contribution of health care utilization, and particularly PSA screening, to differences in disease severity at presentation needs to be carefully studied [22]. If differences in PSA screening and health care access are linked to worse disease at presentation among black men, it becomes increasingly important to understand financial and non-financial factors that limit access to preventive health care among black men. Distrust of the health care system, few minority physicians, and fear of screening procedures and surgery all may factor into reducing access to health care among black men in the broadest sense [23, 24]. Although it is clear that black men are significantly less likely to undergo radical prostatectomy than are white men, the contribution of this difference to differences in mortality rates is more controversial [15].

Few data exist documenting improved survival for men who undergo prostatectomy compared to radiation therapy or even watchful waiting [25]. A clearer understanding of the effectiveness of different treatment options is needed before racial differences in treatment can be clearly linked to racial differences in survival.

Although the majority of studies found no difference in treatment outcome, it is interesting to speculate about the reasons why some studies found worse outcomes among black men. Based on descriptive analyses, the difference in results does not appear to relate to whether the study was conducted in a Veterans Affairs Medical Center or measured PSA failure, disease specific or overall survival – potential explanations for differences in study findings that have been proposed by some authors. There may be some association with time since publication with a lower proportion of studies finding a racial difference in outcome in the last 6 years than prior to 1997. Furthermore, it is interesting to note that only 17% of studies that found a racial difference in outcome included patients who underwent radiotherapy, whereas almost half of studies that found no difference in outcome included this treatment option. Although no definitive conclusions can be drawn from these observations, they suggest that racial differences in outcomes may have been more prevalent in the past and may be more likely to be seen following radical prostatectomy than radiation therapy. With the ongoing emphasis on quality of care, it is interesting to speculate that any greater effect of race on treatment outcomes after radical prostatectomy than after radiation therapy may relate to the greater effect of surgeon characteristics than radiation oncologist characteristics on treatment outcomes. Thus, if black men are more likely to use low quality providers than white men this effect would result in greater racial

disparities in outcomes among men undergoing prostatectomy than men undergoing radiation therapy [26].

This review has several limitations. Although we used multiple methods to identify relevant publications, we may have missed some. Furthermore, it is well recognized that negative studies are less likely to be published than studies with a positive result. However, this publication bias would only serve to strengthen our conclusion that the great majority of studies do not find an association between race and treatment outcome. Several studies did not provide information about elements of study design or results that we had hoped to collect. Furthermore, lack of uniformity of information about disease presentation made it difficult to accurately classify the disease stage of study subjects.

Although black men are twice as likely to die from prostate cancer as are white men in the US, this review suggests that this difference can not be attributed to worse outcomes after treatment. Efforts to address this important disparity should focus on reducing cancer incidence and extent of disease at presentation among African American men as well as improving our understanding of the effectiveness of alternative treatment.

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Table 1. Studies reporting prostate cancer treatment outcomes

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Roach, M et al.[27]	1992	Randomized controlled trials	120 black and 1077 white men from 1976-1985	T1b-T4 *	Radiation therapy (XRT)	Radiation Therapy Oncology Group, Philadelphia, PA	Overall and disease-free survival	After adjusting for pretreatment acid phosphatase, Gleason score, and nodal status, two trials suggest race not an independent predictor of survival, while one trial revealed shorter overall survival time in blacks (p= 0.02).	No (Yes in trial of pelvic and prostate vs. pelvic, prostate + para-aortic XRT)
Austin, JP Convery, K [28]	1993	Retrospective	47 black and 867 white men from 1973-1987	T2a-T2c, T3-T4, and metastatic	XRT	SEER Connecticut Tumor Registry	Overall survival	After adjusting for stage, grade, and age, blacks had a worse 5-year survival than whites (HR 96.74, CI 95% 2.12 - 4413).	Yes
Matzkin, H et al.[29]	1993	Retrospective	57 black and 62 white men (no dates reported)	Metastatic	Hormonal therapy	Study location not reported	Overall survival	Analysis did not adjust for disease characteristics because they were similar between racial groups. No significant difference between blacks and whites in overall survival (no HR reported).	No
Kim, JA et al.[19]	1995	Retrospective	157 black and 489 white men from 1975-1989	T1b-T4*	XRT	Study location not reported	Overall survival	When stratified by stage, blacks did not have worse survival for stage I or II, but did for stage III prostate cancer (no HR reported p= 0.006).	No (Yes in stage III)
Moul, J et al.[30]	1996	Retrospective	107 black and 366 white men from 1975-1995	T1-T3c *	Radical prosta-tectomy (RP)	Walter Reed Army Medical Center, Washington, D.C.	PSA failure	After adjusting for PSA, acid phosphatase, stage and grade, blacks had a higher rate of PSA failure (HR 1.69 p= 0.05).	Yes

Is race associated with outcomes?

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Fowler, J Terrell, F [31]	1996	Retrospective	148 black and 209 white men from 1980-1991	T1b- T4*	XRT or RP	Veterans Affairs Center, Jackson, MS	PSA failure, overall, disease specific and disease-free survival	After adjusting for stage, race had no impact on survival in men (no HR reported).	No
Bergan, R et al. [32]	1997	Retrospective	4 black and 39 non-black men (no dates reported)	Metastatic	Hormonal therapy	Warren G. Magnusson Clinical Center, Bethesda, MD	Overall and disease-free survival	Analysis not adjusted for disease characteristics because they were similar between racial groups. No significant difference in time to disease progression (p=0.43), or overall survival (p=0.57) between blacks and non-blacks.	No
Fowler, J et al. [33]	1997	Retrospective	217 black and 188 white men from 1987-1995	T1b-T4, including metastatic	Hormonal therapy	University of Mississippi Medical Center and Veterans Affairs Center, Jackson, MS	PSA failure	After adjusting for pretreatment PSA, no difference between black and whites in PSA failure rate (no HR reported).	No
Hart, K et al. [34]	1998	Retrospective	571 black and 425 white men from 1980-1993	T1-T3*	XRT	Wayne State University, Detroit, MI	Overall and disease specific survival	After adjusting for age, stage, and grade of disease, no significant difference in overall or disease specific survival between blacks and whites (no HR reported, p=0.66).	No
Iselin, C et al. [35]	1998	Retrospective	115 black and 1204 white men from 1970-1996	T1a- T2*	RP	Duke University Medical and Veterans Affairs Center, Durham, NC	PSA failure and disease specific survival	After adjusting for Gleason score, pathologic stage, preoperative PSA, % prostate involved in tumor and age, outcomes similar in both racial groups. (PSA failure RR 1.567, 95% CI 0.94-2.63; disease specific mortality RR 1.215, 95% CI 0.67-2.2)	No

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Zagars, G et al. [36]	1998	Retrospective	116 black and 1,085 white men from 1987-1996	T1-T3*	XRT	M.D. Anderson Cancer Center, Houston, TX	PSA failure and overall survival	After adjusting for pretreatment PSA, stage, Gleason score and hormonal therapy, no significant difference between blacks and whites (p=0.63).	No
McLeod, D et al. [37]	1999	Randomized controlled trials	187 black and 581 white men from 1992-1993	Metastatic	Hormonal therapy	Zeneca Pharmaceutical Wilmington, DE	Disease-free survival	No effect of race was observed (HR not reported).	No
Hart, K et al. [38]	1999	Retrospective	306 black and 387 white men from 1989-1994	T1a -T2c*	RP or XRT	Wayne State University, Detroit, MI	PSA failure	After adjusting for stage, PSA, Gleason score and type of treatment, blacks had comparable rates of PSA failure as whites. (OR 1.22, 95% CI 0.87-1.72).	No
Powell, I et al. [20]	1999	Retrospective	333 black and 426 white men from 1991-1996	Not provided	RP	Wayne State University, Detroit, MI	PSA failure	No overall difference in PSA failure. However, younger blacks (50-59 and 60-69) had higher rate of PSA failure than younger whites (p = 0.03 and p = 0.0001).	No (Yes for younger men)
Sohayda, CJ et al. [39]	1999	Retrospective	318 black and 1901 white men from 1986-1998	T1-T3*	RP or XRT	Cleveland Clinic Foundation, Cleveland, OH	PSA failure, overall and disease-free survival	After adjusting for pretreatment PSA, Gleason score, clinical stage, family history, type of treatment, and age, outcomes were not significantly different between blacks and whites. (PSA failure OR 1.10 white vs. black, 95% CI 0.85-1.43).	No

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Eastham, J Kattan, M [40]	2000	Retrospective	218 black and 257 white men from 1990-1998	T1-T2*	RP	Louisiana State University Medical Center and Overton-Brooks Veterans Affairs Medical Center, Shreveport, LA	PSA failure	After adjusting for age, pretreatment serum PSA, clinical stage and Gleason score, race had no effect on PSA failure (p=0.65).	No
Powell, I et al. [18]	2000	Retrospective	263 black and 349 white men from 1991-1995	T1a-T2c*	RP	Wayne State University Detroit, MI	PSA failure	After adjusting for Gleason score and PSA, no difference in PSA failure between blacks and whites with organ-confined cancer (RR 0.58 p = 0.41). However, among patients with non-organ confined cancer, blacks had higher rate of PSA failure than whites (RR 1.77 p = 0.005).	No (Yes for locally advanced)
Shekarriz, B et al. [41]	2000	Retrospective	205 black and 288 white men from 1991-1995	T1a-T2c*	RP	Wayne State University Detroit, MI	PSA failure	Blacks with positive surgical margins had worse disease free survival after adjusting for Gleason score, PSA and characteristics of margins (No HR reported p= 0.04).	Yes

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Tarman, G et al. [11]	2000	Retrospective	192 black and 818 white men from 1987-1997	T1-T2c*	RP	Naval Medical Center, San Diego, CA Walter Reed Army Medical Center, Washington, D.C. Madigan Army Medical Center, Tacoma, WA Brooke Army Medical Center, San Antonio, TX	PSA failure	After adjustment for preoperative PSA, age of onset, stage and grade of disease, and military rank, black men with localized disease more likely to have PSA failure ($p=0.04$).	Yes
Young, CD et al. [42]	2000	Retrospective	119 black and 407 white men from 1987-1995	T1-T3*	XRT	Martinez Veterans Administration and University of California, San Francisco, CA	PSA failure	After adjusting for PSA levels, stage, Gleason score, radiation treatment and hormonal treatment, race not associated with PSA failure (no HR reported).	No
Freedland, S et al. [43]	2000	Retrospective	125 black and 148 white men from 1991-1999	T1-T3*	RP	University of California Veterans Affairs Medical Center, Los Angeles, CA	PSA failure	After adjusting for serum PSA, age, Gleason score, surgical Gleason score, and positive lymph nodes, no differences observed in PSA failure between blacks and whites (HR 0.71, 95% CI 0.42-1.20).	No

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Kupelian, P et al. [44]	2001	retrospective	219 black and 717 white men from 1986-1998	T1-T3*	XRT	Cleveland Clinic Foundation, Cleveland, OH	Overall survival	After adjusting for age, stage, Gleason score, pretreatment PSA levels, use of androgen deprivation, year of therapy, radiation dose and radiation technique, race was not an independent factor predicting overall survival. (p=0.80).	No
Thompson, J et al. [45]	2001	randomized controlled trials	288 black and 975 white men (no dates reported)	metastatic	Hormonal therapy	Southwest Oncology Group, Seattle, WA	Overall survival	After adjusting for extent of disease, performance status, bone pain, treatment arm, PSA levels, age, and Gleason score, blacks had a worse outcome prognosis than whites (HR 1.23 95% CI 1.04-1.47).	Yes
Connell, P et al. [46]	2001	retrospective	418 black and 475 white men from 1988-1997.	T1-T4*	XRT	University of Chicago, Chicago, IL	PSA failure, overall and disease-free survival.	After adjusting for PSA, PSA nadir, tumor stage, interval to nadir, Gleason score and age 5-year overall survival, disease-free survival, and PSA failure rates were not significantly different between blacks and whites (HR 1.2, 95% CI 0.8-1.7).	No
Cross, C et al. [47]	2002	retrospective	162 black and 1874 white men from 1989-2000	T1c-T2c*	RP	Brigham and Women's Hospital, Boston, MA Hospital of the University of Pennsylvania, Philadelphia, PA	PSA failure	After adjusting for pretreatment PSA, Gleason score, stage and age no statistical difference in PSA failure after RP (p = 0.70 for low-risk group and p = 0.28 for high risk group).	No

Author	Year	Research design	Sample size	Stage of disease	Treatment	Study location	Outcomes measured	Findings/outcomes	Is race associated with outcomes?
Powell, I et al. [48]	2002	retrospective	229 black and 562 white men from 1990-1999	T1a – T3*	RP	Detroit Medical Center, Detroit, MI	disease-free survival	After adjusting for age, preoperative PSA, Gleason score, and pathologic stage, race had a significant effect on disease-free survival (HR 2.35, 95% CI 1.65-3.33).	Yes
Banerjee, M et al. [49]	2002	retrospective	421 black and 616 white men from 1991-1996	T1c-T2b*	RP	Wayne State University, Detroit, MI	PSA failure	Analysis not adjusted for disease characteristics because they were similar between racial groups. Blacks and whites had similar rates of PSA failure (p = 0.73)	No
Lee, L et al. [50]	2002	retrospective	246 black and 835 white men from 1992-1999	T1b - T2b*	XRT	Memorial Sloan-Kettering Cancer Center, NY	disease-free survival	After adjusting for PSA, Gleason score, stage, hormones and isotope used, race was not an independent predictor of 5-year disease-free survival between blacks and whites. (HR 0.68, 95% CI 0.45-1.21).	No
Grossfeld, G et al. [51]	2002	retrospective	133 black and 1270 white men from 1986-2001	T1-T3*	RP	University of California, San Francisco, CA	PSA failure	After adjusting for age at surgery, Gleason score, PSA, stage, education and income blacks had greater PSA failure.	No